# PSYCHO-SOCIAL FACTORS IN CARE AND REHABILITATION OF DIFFERENTLY ABLED CHILDREN: ROLE OF FAMILY, CIVIL SOCIETY AND GOVERNMENT

## INTRODUCTION

This world is full of human diversity. Individuals differ from each other in their physical, intellectual, emotional and behavioural traits. The words like deaf, lamb, blind, disabled etc., reflect a negative connotation. The term "Disabled person" is more appropriate and reflects the social model of disability. Further the term “Differently Abled” is considered positive and non-offensive intent for the persons with special needs. Earlier, “Disabilities” and “Persons with Disability” had negative connotations and were producing a feeling of offensiveness. So, to reduce the negative consequences “children with disability” has been replaced by “differently abled children.” Differently abled children are those who are different and unique from normal children because they are abled in another way. It doesn’t mean that they are useless and not capable to do anything, rather they are differently abled. “They cannot perform the normal activities in the world because they suffer from physical, mental, emotional or sensory impairments (World Health Organization WHO, 2011).” Disability is a health problem. It may happen to anybody at any time.

According to (report of WHO, 2012) “Disabilities in children include various types of inabilities or impairments like activity limitations and participation restrictions. Impairment is a problem in body function or structure and activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives.”

In the Disability Act 2005 of government of India, ‘disability' in relation to a person is defined as 'a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the state or to participate in social or cultural life in the state because of an enduring physical, sensory, mental health or intellectual impairment.’

The total number of disabled people in world (according to World Report on Disability, 2011) is more than one billion persons today who cannot take full participation in ordinary activities because they suffer from physical, mental, emotional or sensory impairments. This is about 15% of the total world's population. According to the Census of India (2011) there are 26,810,557 people with disabilities who constitute 2.21% of the total population of India. This figure constitutes persons with visual, hearing, speech, locomotors and mental disabilities. There are 23,310,000 people with disabilities in Bihar which comprise 2.24% of the total population of Bihar and about 189,092 in which they constitute 3.24% of the total population of Patna district. The Total number of disabled population in urban areas of Patna district is 82,476 which is 3.28% of total population of urban Patna.

**TABLE-1**
**Population of Differently Abled Children (0-19)**

| Name | Age range | Total Population | % of disabled population out of total population | % of disabled population out of total disabled population |
|---|---|---|---|---|
| India | **Total Population** | **1210854977** | - | - |
| | **Total population of disabled person** | 2,6810,557 | **2.21** | |
| | 0-4 | 12,91,332 | 0.11 | 4.8 |
| | 5-9 | 19,55,539 | 0.16 | 7.3 |
| | 10-19 | 46,16,050 | 0.38 | 17.2 |
| Total | 0-19 | **78,62,921** | 1 | **29.3** |
| Bihar | **Total Population** | **10,40,99,452** | 8.60 | |
| | **Total population of disabled person** | **23,31,009** | **2.24** | |
| | 0-4 | 1,86,314 | 0.18 | 8.0 |
| | 5-9 | 2,57,526 | 0.25 | 11 |
| | 10-19 | 4,89,183 | 0.47 | 21 |
| Total | 0-19 | **9,33,023** | 0.90 | **40.0** |
| Patna | **Total Population** | **58,38,465** | 5.6 | |
| | **Total population of disabled person** | **1,89,092** | **3.24** | |
| | 0-4 | 14,476 | 0.25 | 7.7 |
| | 5-9 | 19,444 | 0.33 | 10.3 |
| | 10-19 | 39,866 | 0.68 | 21.1 |
| Total | (0-19) | **73,786** | **1.26** | **39.0** |
| Patna urban | **Total Population** | **25,14,590** | 43 | |
| | **Total population of disabled person** | **82,476** | **3.28** | |
| | 0-4 | 5,401 | 0.21 | 6.5 |
| | 5-9 | 7,580 | 0.30 | 9.2 |
| | 10-19 | 17,383 | 0.69 | 21.1 |
| Total | **0-19** | **30,364** | **1.21** | **36.8** |

Source- Census, 2011, Registrar General, Census Commissioner, govt. of India, New Delhi.

Differently abled children of total disabled (age group 0-19) in Bihar is 93, 3,023 which constitutes 40% out of the total disabled person. In Patna, they are 189,092 which accounts for39% out of the total disabled persons. 30,364 in children are differently abled in urban area of Patna district sharing 36.8% out of the total disabled persons. Table-1 clearly shows that maximum numbers of differently abled are present in our society from childhood. "One in every 10 children is born with or acquires a physical, mental or sensory disability. So, India is probably home to millions of disabled children" (Addlakha, 2007).

Differently abled children are one of the most marginalized and excluded groups in the society. They have a different kind of relationship with their social environment because the stigmas attached with their disability make them a burden. Being members of the society, they learn from their childhood to cope with the rejection by the society and family due to their disability. Facing discrimination in everyday life in the form of negative attitudes toward them by others, such as exclusion from playing by their peer group and lower level of treatment in educational institutions, they experience social isolation, strong feelings of frustration, anger, sadness and shame which lead to psychological problems in their lives such as anxiety, depression, and low self-esteem as well as behavioral problems of maladjustment. Differently abled children face difficulties in forming and maintaining social relationships with others due to their level of disability which limits and restricts their participation in everyday activities with their peers. They face difficulty in picking up social cues. As a result, children with disabilities lose confidence in their ability to make friends and to participate in activities with other children of their age and subsequently affect their mental health. They experience violence, withstand fear, humiliation, and face extreme deprivation. In all of mentioned situations, children's psycho-social and physical development is interrupted. Their security and trust are threatened and subsequently, their hope and confidence may be severely affected.

Disability affects the life of children very severely because it stifles their childhood growth which is integral for their overall development. "Differently abled children are categorized under the age group of 0-14 years. Need of their service and care are decided on the basis of the degree of their impairment" (Children in India, 2012).

Care and rehabilitation programmes are the processes of minimizing and reducing the impact of disability on individual. Assessment of children for rehabilitation should be based according to

their needs. Care and rehabilitation programmes are needed for the betterment and enhancement of overall developments of children. These programmes may be formulated and constructed as the way of treating differently abled children in a positive way so that they feel strong and comfortable. Care is provided by the parents, other family members and in few cases by institutional caregivers, but rehabilitation may be provided by the joint and integrated efforts of family, civil society and government agencies.

Rehabilitation may be defined as means to restore useful energies of life through various programmes such as therapies, special training and education. It maximizes the physical and mental capacity of children so that they can enjoy life. The children with disabilities have additional needs and capacity despite their disabilities (Capper, 1996 and Pueschel et al., 1988).

Disability of a child is a medical, psychological and social challenge for the family members and care givers. Family plays a pivotal role in creating friendly environment for differently abled children and shapes their personality. Parents are the pillars of this unit. Parents' responsibilities are to raise their children with inculcation of social and moral values. When a child is disabled, his/her responsibility becomes crucial. Being the parents of a disabled child is stressful and requires changes in their attitudes and life styles (Thompson, 2000). Devoting time, spending money and energy are required for caring the disabled child. Besides this, it is difficult for the parents to develop self-esteem, social skills, and providing appropriate education to the differently abled child. So, how to reduce the psychological problems faced by the parents and family, and how to motivate parents and family to take care of their disabled children are big questions**.**

Apart from the family, civil society plays a significant role in the care and rehabilitation for children with disabilities. Civil society occupies the social space between the family and the state. Civil society organizations provide voluntary services. Some organizations provide institutional care to the differently abled children. It promotes welfare and community involvement for these children.

In addition to family and civil-society, the role of Government in care and rehabilitation of differently abled children is also important. Government provides different kinds of facilities through schemes, policies and laws like health care, educational facilities and vocational training

etc. It provides facilities to such abled children through non-governmental organization as well as through its own agencies.

Unfortunately, the differently abled children of all sections of the society do not get care and rehabilitation as required. Several questions may arise such as; who are these children who get a chance for care and rehabilitation provided by the government and who amongst them are left out? What are the psychological problems they face to become a normal human being? What are their special needs and whether they are properly assessed to identify those needs? What are the special abilities among them which are required to find and to be developed through various rehabilitation programmes? What are the problems of parents and their family members? What types of psychological and social problems parents and family face? What are their limitations in care and rehabilitation? The psychological and social problems of parents are required to be assessed. As the government is one of the major sources of care and rehabilitation, what are the problems of the government agencies and how far the policies and programmes are suitable for the differently abled children? These questions need to be answered. Apart from the family and government, the role of civil-society organizations should also be assessed. There are various registered and non-registered civil-society organizations also called N.G.Os (Non-Governmental organizations). Their contribution and constraints should also be assessed.

## REVIEW OF LITERATURE

### Psycho-social problems of differentially abled children

In our society differently abled children are neglected and this fact still looms large. Due to this reason differently abled children and their family have been facing psycho-social problems which are reflected in some studies. These problems create barriers in way of care and rehabilitation of differently abled children.

Persons with physical disability showed more inferiority complex than those without any defects. A blow to one's body image can create inferiority complex. The feelings of incapacitation may give rise to lack of confidence in one's abilities and bring in a host of psychological barriers in personal and social adjustments (Mathew, 1974).

Rao has also supported through his study on the orthopedically handicapped children, that the handicapped group had exhibited low self appraisal, passivity, low ego strength and projected aggressiveness, to be more worrying type, exhibiting more self condemning attitudes and submissive reactions (Rao, 1981). Further, Ghai and Ittyerah also supported the above findings, (Ghai and Ittyerah, 1980). Differently abled children had experiences of physical, emotional and verbal bullying by other children. This fear of bullying had changed their sense of self and social relationship (Watson et. al., 1999).

In some study it has been found that the vulnerability to abuse, neglect and violence experienced by intellectually disabled children. When negative experiences get in childhood then their development are badly affected (Emerson, et al., 2012). Usha Bhatt found fear mixed with panic and anxiety in majority of the cases (70%) and the rest had inferiority and guilt feelings (Bhatt, 1963). However, other studies have indicated some other psychological problems of disabled person such as withdrawal, sensitivity, shy, reserved, secretive and nervous in character.

On the whole, the majority of the handicapped had hypochondriacally features, narcissistic traits, self centeredness, poor interest in human beings, low adaptability to surroundings, and lack of emotional warmth, weak ego, poor imagination and limited interest in comparison to the normal able-bodied subjects (Prasad et al., 1971). The impact of the disability on family as well as individual's adjustment has been found to be a feeling of self doubt and guilt may be complicated by others factor like poverty, family size and absence of social support (Peterson and Mathieson, 2000).

**Psycho-social factors of family of differentially abled children**

The disability is a great problem not only for child but also for the family. Becoming the parent of a child who has a disability is a time of great stress and change (Thompson, 2000). Such as, the parents of differently abled children face various types of psycho-social problems and pressures, the higher amounts of stress and greater demands of caring. The everyday tasks of feeding, toileting, travelling and communicating are much more physically and emotionally demanding (Ambert, 1992; Featherstone, 1981). ). Dervishaliaj in his study noted or cited the research conducted by Martin & Colbert, (1997) in which they have pointed out that according to research; parents' psychological well-being is strongly affected by their child's primary diagnosis as

disabled. Shock, denial, disbelief, grief are parents' common reactions in this case (Dervishaliaj, 2013).

Stress attributed family of differently abled children was about double stress when the youngest sibling without a disability (Baxter et al., 2000). It is also discussed that severity of behavioural problems and lower family incomes influenced whether the child meets the expectations of the parents (Johnston et al., 2003).

Some contrasting evidences have been found that higher socio-economic status (SES) was associated with increased parenting stress (Baker, 1994). Some researchers found in their studies that differently abled children's are kept hidden away at their home, denied basic rights of mobility, education and employment by family members (Janardhana, et. al., 2011). In this study it was also reflected that physical abuses with differently abled children and could not get basic right of care which are important in overall development.

Sethi revealed that high level of stress and burden was associated with increased level of disabilities. Multiple factors of stress seem to be responsible for the stress and burden experienced by the caregivers. Amongst the mother parents, they perceive more stress and burden in caring their disabled children than fathers (Sethi et al., 2007). This is also explained in literature that having a child with a developmental disability does present more challenges, including emotional strains, financial hardships, career disruption, social isolation, and worry about the child's future (Seltzer & Kraus,1994). In some study it is showed that most of the respondents reported late or retarded growth. The main reason given was that there was lack of facilities nearby and either had no source of income or their income was below Rs. 500/- per month (Sethi, et. al., 1980).

These studies show that differently abled children and their family face many psycho-social problems due to disability. Some studies focused on the social stigma and lower socio-economic status which influences care and rehabilitation of differently abled children.

## Care and rehabilitation

Every Differently abled child has right to be cared and rehabilitated, to be good human being and a responsible citizen of the society. For this, they have special **needs** for care and rehabilitation Thompson found that children with disabilities need additional items such as special clothing, equipment, communication devices and bathroom aids (Thompson, 2000). Family centered

rehabilitation services for children with disabilities provides valuable knowledge in assisting mother's understanding of the nature of their children's disability and how they can be managed . It is also to improve social and educational opportunities for disabled children (Maloni K. Priya, et.al, 2010). The responsibilities associated with the care of disabled children, researchers have found many impacts on parent's psychological, physical, financial and social well being over time (Seligman and Meyerson, 1982). Institutional care for the disabled has been growing during the last two decades. It is not only entirely suitable for differently abled person's individual needs, dignity and independence. Community based rehabilitation has picked up pace and contribute toward greater independence and self sustainability of the disabled. It helps to address the ugly forms of discrimination existing in the community (Naidu D. M., et. al., 2015).

**Role of family, civil-society and government**

Very few studies have been done on the on the role of family, civil-society and government. Firstly, the most important role in care and rehabilitation of differently abled children of family, because primary care and rehabilitation given by parents and family and institutional care others rehabilitation depend on their attitude. The parents' role of nurturing through their adopted parenting style and exerts a powerful influence on the psychological development of their children (De Souza & Paul, 2013).

Both the State and Central Governments have been passing various schemes for the benefits of the disabled persons. In 1992 'The Rehabilitation Council of India' was established for assuring quality service from qualified professionals for the disabled. In 1995 The Disability Act was passed and in 1999, 'The National Trust' was established for giving institutional care to the disabled. Disability is an important public health problem. There is a large gap between the services felt and received by the disabled (Kumar & et.al, 2004). Trivedi has expressed her concern for the undesirable concentration of services in isolated institutions, especially in matter of education of the disabled (Trivedi, 1981). Dey has pointed in his work that adequate legislation and its proper implementation will go a long way in ameliorating the plight of the physically disabled in India (Dey, 1981). NGOs have played key role in the provisioning of community based disability service (Lang, 2000). Kandyomundo et al found that participation by local NGOs has so far been very crucial in the implementation of community based programme in Africa but as government take on more responsibilities. The challenges for NGOs are to lead the way in sharing

their expertise of how to work in participatory way at community level (Kandyomundo, et.al., 2010). In most cases NGOs depended on donation for the required resources (Mazibuko, 2000).

Singh and Sethi conducted a study with the objective to define role of NGOs in promotion of education of disabled in Jammu district. They found that there was increasing awareness and sensitivities towards differently abled children for past few years. But resources are limited for them. Various NGOs have been working in concerned areas to enable the differently abled children to live and grow up with dignity and become worthy citizens of nation. They also observed that a large number of differently abled children have special needs. The need of majority with little attention as given by members of civil-society for the benefit of differently abled children have been found (Singh and Sethi, 2012). Some form of community based or community orientated rehabilitation is the only feasible strategy to attempt to meet both the immediate and physical needs (Helen Jackson, 1988).

The role of government should be robust in care and rehabilitation of differently abled children but it was found that only 60 percentage funds were utilized by 53 selected districts in India during 2007-10. Some districts of Bihar did not release the funds due to lack of proposals sent by state government to Ministry of Social Justice and Empowerment, government of India. In this situation a part of scheme has been implementation by few NGOs in partnership with government which are very small and insufficient to work on their own (Planning Commission Programme Evaluation Organization, Government of India, 2013).

Care and rehabilitation of differently abled children is serious concern for all countries. Families all across the globe also face external stresses, which may impact on their ability to care. Although efforts are on to bring into the rights of disabled perspectives for people with disabilities. Studies revealed that families, civil society and government play a role in care and rehabilitation of differently abled children, but yet there is clear evidence that what exactly will be the role of civil-society and government? There is a little focus on the psycho-social problems of parents. Moreover, no such type of study related to role of family, civil society and government for care and rehabilitation of differently abled children has been conducted in Patna district of Bihar so far. Therefore, it is an urgent need to identify those factors which hinder the care and rehabilitation of differently abled children. Thus, in this context, this study will be an exploration among the differently abled children and their care and rehabilitation. The proposed study is an attempt to

determine the psycho-social factors that influence care and rehabilitation of disabled children. This study would also explore as to what are people's understanding about role of the family, civil society and government in care and rehabilitation of differently abled children. It will be also useful in psycho-social adjustment of disabled children and might be helpful for care and rehabilitation management of the policy makers.

There is lack of adequate data on such issues. As, Nidhi singhal found that and The Registrar General of India (2001) also agreed that "the Indian data is unreliable due to few well field investigators and issues of social stigma" Nidhi (2009). Unreliable data creates barrier in the way of rehabilitation programme and government agenda related to differently abled children. Rehabilitation programmes run by State, Central government and civil-society. Besides ensuring that available benefits reach them, more resources from local state, national and international agencies, government and non-government organizations need to be mobilized. There is an urgent need to ensure the provisioning of rehabilitation for the differently abled children. Thus, certain questions are arising to be answered which are as follows:

I. What are the psycho-social factors behind care and rehabilitation of differently abled children by the parents, other family members of family, people from civil-society, NGOs and government etc?
II. What are the psycho-social problems related to differently abled children itself and the types of special need of differently abled children and how are they assessed?
III. What are the impacts of society in terms of social stigma and neglect of such person?

## AIMS AND OBJECTIVES

### AIMS

To improve the level of care and rehabilitation of differently abled children and to bring overall awareness in the society, family and government officials regarding the uses of the differently abled children. So that they can live a dignified social life and could face the challenges of life.

### OBJECTIVES

1. To find out the psychological and social factors behind care & rehabilitation of differently abled children.

2. To study the role of family members regarding care & rehabilitation of differently abled children.
3. To examine the role of civil-society in term of care & rehabilitation of differently abled children.
4. To assess the role of government in term of care, rehabilitation and welfare of differently abled children.
5. To explore the conducive social environment and support system for the care and rehabilitation of differently abled children.

## METHODOLOGY

### Geographical Area and the Universe

The geographical area of this study will be municipal area of Patna district of Bihar. The universes of this study will all differently abled children between the ages of 06 to 14 years studying in government primary to high schools. The universe also covers their parents, family members, care givers in case when differently abled child depends on care givers and civil-society organization registered under the society act and non-registered and government offices/agencies/departments those who are working for differently abled children at Patna.

### Sample and Sampling Techniques

Identification and selection of subjects as sample will be based on the list of differently abled children taken from the head office of the Sarva Siksha Abhiyaan, SSA, Patna, because inclusive education is running by SSA in government schools for differently abled children. Firstly, schools will be divided in three group primary, middle and high from stratified sampling technique. Then, form that list a sample of two hundred children (N=200) both girls and boys in these school will be selected by random sampling technique. All types of differently abled children will be included in sample. Selection of primary to high schools in Patna urban area will be based on list of differently abled children which are studying in those schools. All parents, family members and care givers will contacted though selected children from the list. Then, list of civil-society (NGOs) and government offices/agencies/ department will be collected by Bihar State Social Welfare Advisory Board, Bihar. Again, key persons of civil societies and

government departments who are working in concerned areas will be selected using purposive technique respectively.

**Sampling Design and Unit of Study**

| S. no. | Unit | Description | Sample size | Sampling technique |
|---|---|---|---|---|
| 1. | Differently abled children | Age group 06-14 year's children both girls and boys and who are studying in primary to high govt. schools in Patna. | 200 | stratified random technique |
| 2. | Parents /family members/care givers | Parents or family members of differently abled children | 200 | Through selected children |
| 3. | Special teacher | Teachers who are teaching differently abled children in government schools. | Adequate no. of person as per need and availability. | Purposive technique |
| 4. | Key person of civil society | Those who are working for differently abled children. | | |
| 5. | Key person of government office/agencies/department | | | |

**Tools**

Four types of interview schedule will be prepared for differently abled children, parents/family members/caregivers, key person of civil-society and government offices based on aims and objective of this study after a pilot study. Pre-test will be done and schedule will be validated before going to the field for final data collection.

**Technique of Data Collection**

Through the selected schools in the list of differently abled children will be identify there after their parents/family members/caregivers and special teachers will be indentified and there after contacted. Self prepared interview schedule will be applied on children. Those differently abled children will be not able to respond there information will be collection from respective teachers

and parents. Similarly special teacher and parents as well as key person from civil-society and government offices will be interviewed.

**Data Analysis**

Collected data will be coded and entered computer using "ms-excel" or "SPSS" software. Appropriate statistic will be used as per the need of study.

## PLAN OF CHAPTERISATION

There will be following tentative chapters:

1. Introduction
2. Literature review
3. Methodology
4. Psycho-social factors behind care and rehabilitation of differently abled children
5. Role of family in care and rehabilitation of differently abled children
6. Role of civil-society in care and rehabilitation of differently abled children
7. Role of Government in care and rehabilitation of differently abled children
8. Discussion, conclusion and recommendations

There will be a section for reference and another appendix which will include the interview schedules used in the study.

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